Council for
Intellectual Disability

POSITION STATEMENT

NDIS Quality & Safeguarding Framework

April 2015

This position statement is the submission of
NSW Council for Intellectual Disability
on the consultation paper prepared by
the NDIS Senior Officials Working Group
for the Disability Reform Council.

Contact
Jim Simpson
Senior Advocate
jcsimpson@optusnet.com.au

www.nswcid.org.au   www.facebook/nswcid   https://twitter.com/nswcid

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Please Note:

Where text is in *purple italics*, this is a direct quote from a person with an intellectual disability who attended the National Roundtable on Quality and Safeguarding and people with intellectual disability.

Background Information

What informed this position

This position is based on:

- the experience of people with intellectual disability and their families, NSWCID's long experience in systemic advocacy, and

- discussion at our National Roundtable on Quality and Safeguarding and People with Intellectual Disability, held in March 2015.

Why a very rigorous framework is needed

- People with intellectual disability are over 60% of NDIS participants and are very vulnerable to abuse and neglect.

- Capacity for choice and control will not just happen for people with intellectual disability. It should gradually grow over time.

- The implementation of the NDIS is an enormous undertaking.

- These factors point to the need for a very rigorous quality and safeguards framework in the early years of the NDIS.

- The spending on a rigorous framework would be an investment that would yield considerable budgetary savings over time.

KEY POINTS

1

Principles and scope of the framework

The principles for quality and safeguarding should take account of the need for people with intellectual disability to have considerable support to develop their abilities for choice and control.

Risk does not just relate to kinds of support. It also relates to ability to understand and act on mistreatment.

The scope of the framework needs to include ILC services, not just Tier 3 participants.

2

Information for participants

People with disability and their natural supports need information available in a range of formats and from sources that suit their individual needs. For example, some people will be comfortable with a centralised website, others will rely on a local, trusted community organisation.

3

Building natural safeguards

Building natural safeguards for people with intellectual disability requires a rigorous and multifaceted strategy whose focus includes families as well as people with intellectual disability. This needs to include particular focuses on people living isolated lives on society's fringe, on the role of advocacy and other community groups in developing people's abilities in self protection, choice and control, and on the role of support providers in developing friendship networks.

4

Advocacy and quality and safeguarding

Individual and systemic advocacy are essential parts of a quality and safeguarding framework.

The final framework should include a plan to ensure an adequate supply of advocacy around Australia.

5

NDIA Provider registration

Registration requirements should be related to risk but risk is related to vulnerability of service users not just service type.

Providers should generally be required to undergo independent quality evaluation based on the experiences and outcomes of users and observation of service practices.

6	**Systems for handling complaints** While providers should have accessible complaints mechanisms, an independent complaints body is also essential. However, in view of the many reasons why people with intellectual disability do not make complaints, the independent body needs to focus at least 50% of its role on proactive monitoring, reviews and inquiries. There should be a community visitor scheme linked to the independent body. The independent body should be focused on the NDIA as well as providers and should have a role in linking people to and up skilling mainstream complaints bodies. The central focus of these structures should be on quality of outcomes for people with disability and active respect for their rights rather than on the policies and procedures of providers.
7	**Ensuring staff are safe to work with participants** There should be mandatory reporting of allegations and reasonable suspicion of serious abuse and neglect in support providers. Staff should need vulnerable people clearances based on a wide range of information similar to the current South Australian system. The available information should include a centralised database of findings of misconduct against individual disability workers. Prospective employers should be able to contact previous employers via this database.
8	**Safeguards for participants who manage their own plans** The NDIS should provide a range of encouragements and supports for self management including developing people's skills in risk enablement, information packages for participants, skilled assistance with implementation of a plan and fostering development of registered plan managers and user-led organisations that assist people to self manage. The nominee regime in the NDIS legislation should be applied rigorously to confirm proposed nominees have the required attributes. Self managers should not be confined to using registered providers of support but unsafe workers should be excluded from working for a self manager.

9

Reducing and eliminating restrictive practices

Workforce skills - The NDIA needs to develop a strong workforce of behaviour support practitioners who meet rigorous criteria for professional qualifications and competencies.

The NDIA needs to maintain the structures or at least roles of State/Territory regimes that underpin quality behaviour support.

Authorisation - Restrictive practices should only be allowable in the context of high quality behaviour assessment and support.

Any prescription of psychotropic medication to a person with intellectual disability should be made by a doctor with established competencies in intellectual disability mental health.

Restrictive practices should only be permissible with the authorisation of an independent official such as a senior practitioner or a guardian who has been appointed for that purpose.

If there are to be any situations where providers have the power to authorise restrictive practices, there need to rigorous safeguards in relation to the skills of the authoriser, independent monitoring and/or involvement in decisions, and review rights.

Monitoring and reporting - There should be mandatory reporting of restrictive practices similarly to the Restrictive Interventions Data System in Victoria.

A senior practitioner should monitor the data and conduct reviews and spot audits aimed at enhancement of providers' behaviour support and intervening where restrictive practices are being used inappropriately.

Which restrictive practices? - The proposed framework is focused predominantly on restraint and seclusion. There are other restrictive practices such as monitoring devices, confining a person to their residence and apprehended violence orders.

Further consideration is needed of which practices are covered by the NDIS framework and how.

Chemical restraint versus mental health treatment - This is not a clear distinction. The framework needs to include a focus on improving doctor skills in intellectual disability mental health and collaboration between doctors and behaviour support practitioners.

10	**Oversight of the NDIS <u>and the NDS</u>** There should be an independent Disability Commission oversighting the NDIS and the National Disability Strategy. The Commission's roles should include those in this Position relating to complaints, monitoring and review, mandatory reporting of serious incidents, working with vulnerable people clearances and restrictive practices. It is essential that the Disability Commission is a stand alone body so that it can create a culture and practices that are fit for purpose.
11	**Implications of national framework for existing State/Territory rights protection bodies** Care is needed that valuable roles played by State/Territory rights protection bodies are not lost with the implementation of the NDIS, for example the role of the NSW Ombudsman in reviewing deaths in supported accommodation.

Who we are

NSW Council for Intellectual Disability (NSWCID) has been a peak body representing the rights and interest of people with intellectual disability for nearly 60 years. NSW CID is funded by the NSW Government as a systemic advocacy and information service.

People with intellectual disability lead NSW CID. Since 2004, the majority of the board must be people with intellectual disability and the chairperson has been a person with intellectual disability. Other board members include family members and advocates.

In developing this position statement, NSWCID has benefitted greatly from input of people with intellectual disability and a wide range of other leaders in the disability field who attended our National Roundtable on Quality and Safeguarding and People with Intellectual Disability. See list of attendees in the Appendix.

We need this framework to protect the rights of people with intellectual disability.

Key Points

This position is based on the experience of people with intellectual disability and their families, NSWCID's long experience in systemic advocacy and discussion at our National Roundtable on Quality and Safeguarding and People with Intellectual Disability.

Why a very rigorous framework is needed

People with disability in Australia have a history of inadequate support and a high level of vulnerability to neglect, abuse and exploitation.

The existing research suggests that children and young people with disability experience abuse at rates considerably higher than their peers who do not have disability. The most reliable international prevalence studies found the risk of abuse for children with disability to be approximately 3.5 times higher than for children without disability in both the USA and World Health Organization European countries. For children with intellectual disability, communication impairments, behaviour difficulties, and sensory disability, studies show even higher rates of abuse (Robinson 2014).

For adults, a review of available research suggested that people with disability had 1.5 times the experience of violence of adults without disability (1.6 times for people with intellectual impairments and 3.9 times for people with mental illnesses). The reviewers said that more robust studies were needed. (Hughes and others 2012)

Frohmader, Dowse and Didi (2015) reviewed prevalence studies in relation to violence against women with disabilities. Women with disabilities in residential services frequently experienced sustained and multiple episodes of violence, particularly sexual violence. More than 70% of women with disabilities had been victims of violent sexual encounters at some time in their lives.

People with disability commonly have not had the opportunity to develop their skills for choice and control and self protective behaviour. On the contrary, people with disability commonly have lived lives with very limited choice and control and a high level of dependence on support providers. All these factors apply particularly to people with intellectual disability whose intellectual impairments impede their ability to take control of their own lives. Family members, who are often key advocates for people with intellectual disability, come from a history of being expected to be grateful for support that is provided and many have narrow horizons and limited confidence to pursue grievances.

People have been living in a routine bubble – with no choices.

The NDIS, with its emphasis on choice and control, should gradually improve the capacity of people with intellectual disability and their family advocates to take control of their lives and speak up for a good life. However, this will be a slow and gradual process.

People with intellectual disability make up 60-70% of NDIS participants. Their vulnerability and needs should therefore carry considerable weight in developing the quality and safeguarding framework.

Also, the framework needs to take account of the extra disadvantage and needs of groups including women, parents who have disability, Indigenous people and those from CALD backgrounds.

The early years of the NDIS will be marked by great challenges in developing the scheme's systems, a massive expansion of workforce and enhancement of the inadequate skills of the current disability workforce.

The combination of all these factors means that, at least for the early years of the NDIS, a very robust and multifaceted quality and safeguarding framework is needed. In this position statement, NSW CID provides its views about what that framework should look like.

The framework should be periodically reviewed, say every five years. It may be that, as people with disability and their families become better equipped to exercise choice and control and as the disability workforce develops, the framework can be relaxed to some degree.

However, it would be perilous to create a framework at this stage which presupposes choice and control of high quality supports by people with intellectual disability.

People with disability in the past have been taken for a ride.

At a superficial level, a rigorous quality and safeguards framework will be expensive for Government. However, the money put into the framework will be an investment that will yield both better lives for people with disability and budgetary savings for Government. Examples of budgetary savings include:

- enhanced quality and hence cost effectiveness of disability support
- increased independence of people with disability and hence less need for funded support
- greater use of self management approaches which the Productivity Commission saw as leading to less use of funded support
- more efficient NDIS practices
- early warning of problems in providers and NDIS systems allowing early remedial action
- early and efficient resolution of complaints and conflicts
- minimising abuse and the range of legal system costs flowing from abuse
- enhanced action on the National Disability Strategy and hence less reliance on NDIS supports

Key Points

People with intellectual disability are over 60% of NDIS participants and are very vulnerable to abuse and neglect.

Capacity for choice and control will not just happen for people with intellectual disability. It should gradually grow over time. The implementation of the NDIS is an enormous undertaking.

All these factors point to the need for a very rigorous quality and safeguards framework in the early years of the scheme.

The spending on a rigorous framework would be an investment that would yield considerable budgetary savings over time.

Discussion

Principles and scope of the framework

NSW CID agrees with the presumption of capacity. However, people with intellectual disability need access to very considerable support and skills training to make this presumption and choice and control real.

What happens to some people who look skilled but still need help?

In many cases, fully supported or substitute decisions may still be occurring and this should be acknowledged with appropriate safeguards. The current minimal use of the nominee system by the NDIA should be reviewed.

NSWCID also agrees with safeguards being proportionate to risk. However, we emphasise that this is not just about the kind of support being provided, eg support with personal hygiene versus handyman services. Equally important is the vulnerability of the individual related to factors such as cognitive impairment and communication skills.

Scope of the framework – The framework proposal tends to use the word "participants" rather than people with disability. However, we understand that the framework is generally intended to apply to Tier 2 of the NDIS (now called ILC) as well as Tier 3. We support this approach. In particular, we see it as important that the following safeguards apply to ILC services – access to advocacy, independent quality evaluations of providers, ensuring staff are safe to work with vulnerable people, and complaints, monitoring and independent oversight.

Key Points

The principles for quality and safeguarding should take account of the need for people with intellectual disability to have considerable support to develop their abilities for choice and control.

Risk does not just relate to kinds of support. It also relates to ability to understand and act on mistreatment.

The scope of the framework needs to include ILC services, not just Tier 3 participants.

Information for participants

Key features of an NDIS information system for people with intellectual disability include:

- information in a range of accessible formats including web based, pictorial, easy read and video
- suitable information for families and other natural sources of support
- capacity to obtain specific and/or local information by telephone or face-to-face
- information being available from local community organisations that are grounded in and have credibility with their local communities
- information being available in culturally appropriate forms and in community languages including Indigenous languages. See First Peoples Disability Network (2013).
- information that is developed by an independent and trusted source that has specialist knowledge on intellectual disability
- outreach and engagement with people who will not naturally be aware of the NDIS or seek support from it
- a capacity for people with disability to share information and experiences in a range of ways including through groups fostered by disability support organisations
- public availability of quality evaluation reports prepared under any provider registration requirements

Key Points

People with disability and their natural supports need information available in a range of formats and from sources that suit their individual needs. For example, some people will be comfortable with a centralised website, others will rely on a local trusted community organisation.

Building natural safeguards

Questions

- Are there additional ways of building natural safeguards that the NDIS should be considering?
- What can be done to support people with a limited number of family and friends?

People are unsure of what they can do.
They have always been told what they can do.

NSW CID supports each of the methods of building natural safeguards outlined in the proposed framework. We also emphasise the following:

- Consideration of these questions needs to squarely include people living on society's fringe who will often lack positive relationships with family or friends, be suspicious of workers and agencies and reluctant to identify as having a disability. The first step here will often be for a worker to spend considerable time building a relationship of trust with the person. The NDIS needs to establish a robust strategy for this, for example by dedicating some specialist local area coordinators to this role. See Jim Simpson's opinion piece at www.everyaustraliancounts.com.au/opinion/ndis-fringe-equity-access/

- Cultural and linguistic issues will be very relevant to what will work in building natural safeguards. For Indigenous people, see First Peoples Disability Network (2013).

- In view of the pace of rollout of the NDIS, varying planner skills and time pressures on planners, we are sceptical about the extent to which planners will be able to ensure real choice and control by people with intellectual disability. Ongoing support by advocates or others plus skill building are needed for this. People with intellectual disability need individual support prior to and during their first planning discussion, not only once they have a plan.

- Capacity building is essential. Advocacy groups that focus on developing self advocacy skills in individuals and in group work play key roles in building natural supports. This includes in developing people's understanding of their rights and how to make complaints.

- Emphasis needs to be placed on establishing and maintaining a network of supportive friends in the lives of people with intellectual disability. This needs to be a key part of the role of disability support providers and occur at transition points such as leaving school. Training programs for disability support workers need to include skills development in building relationships.

- For people who have limited family and friends, there can often be great challenges in building natural relationships. There are similar challenges for people whose family and friends tend to have a negative influence on them as is the case for many people with intellectual disability who have contact with the criminal justice system; often these individuals would benefit greatly from a friend who is a positive role model and mentor. Citizen advocacy and youth mentoring are two programs that have grappled with these issues over time. (NSWCID and IDRS 2001 section 4.6)

- Support providers need to have rigourous processes for very regular input from people with intellectual disability, with appropriate support, into decisions around the way in which the support provider operates.

- Self protection is the best defence against abuse. People with intellectual disability need access to ongoing skills development in relation to understanding neglect, abuse and exploitation and how they can respond to it.

- People with intellectual disability generally need considerable support to develop their capacity to exercise choice and control. This requires skills development, supported decision-making, and opportunities for choice and control starting with routine decisions that arise throughout a person's day.

- Risk enablement - Every planning process with an individual should include a discussion of what might go wrong and strategies to safeguard the individual.

- Parents need positive role models and support from the day they find that their child has an intellectual disability. Other parents are generally the best source of support and education. For many older parents, they are understandably suspicious and sceptical about change including the introduction of the NDIS. Many parents need support and education if they are to be a strong natural safeguard. Two key focuses right from early childhood are: building family capacity to take and safeguard risks so as to develop their child's independence and capacity for choice; building family capacity to identify and respond to signs of possible abuse and neglect.

- Disability support organisations have potential to be key promoters of natural safeguards.

- Safeguarding is the responsibility of the whole community. Through Tier 1 of the NDIS and the National Disability Strategy, there is the opportunity to educate and engage the wider community about their role in creating an inclusive community which prevents the abuse and neglect of people with intellectual disability.

Everybody must choose their support person, it is up to us.

Key Points

Building natural safeguards for people with intellectual disability requires a rigorous and multifaceted strategy whose focus includes families as well as people with intellectual disability.

This strategy needs to include particular focuses on people living isolated lives on society's fringe, on the role of advocacy and other community groups in developing people's abilities in self protection, choice and control and on the role of support providers in developing friendship networks.

Advocacy and quality and safeguarding

I can speak for myself but sometimes I need someone to explain things in layman's terms.

Whilst NSWCID understands the reasons Governments saw advocacy as separate to the Quality and Safeguarding Framework, we feel that advocacy is an essential part of any consideration of quality and safeguarding.

Independent, community advocacy groups have essential roles to play in quality and safeguarding. These roles complement those of other quality and safeguarding mechanisms.

Central to the value of advocacy is that it is independent and community-based. When people with disability and their families have concerns about providers of disability support, mainstream services and statutory bodies, it is advocacy bodies that they tend to go to first and see as a trusted ally.

Key roles of advocacy in relation to the NDIS and its complementary National Disability Strategy include:

- development of self advocacy skills and peer support
- modelling leadership roles by people with intellectual disability
- supporting people to access the NDIS and step through NDIS processes (Joint Standing Committee on the National Disability Insurance Scheme 2014; Clift 2014)
- supporting people with intellectual disability and their families to pursue grievances with support providers and mainstream services including accessing independent complaints mechanisms
- speaking up for people whose disabilities impede capacity and confidence to pursue grievances
- providing an independent voice in decisions about supports for people with complex and challenging needs
- systemic advocacy to improve policies and practices of support providers, the NDIA and mainstream government and community agencies
- systemic advocacy for law reform and broad social reform

At the Roundtable, there was strong support for the need for community advocacy bodies, from participants including the NSW and Commonwealth Ombudsmen, the Victorian Disability Complaints Commission and Public Advocate and the President of the Australian Society on Intellectual Disability.

Taking NSWCID as an example in relation to systemic advocacy, in recent years, we have taken a leading role in raising the profile of key system failures for people with intellectual disability and galvanising action on those failures. For example,

- Disability support services for offenders with intellectual disability in NSW – Our joint work with the Intellectual Disability Rights Service on *The Framework Report* 2001 was a key contributor to people with criminal justice involvement becoming a priority client group for disability services including a specialist Community Justice Program for 400 people with complex offending behaviour.

- Our advocacy, with medical allies, on health inequalities for people with intellectual disability has had a major role in:

    o Establishment of items in Medicare for annual health assessments of people with intellectual disability

    o NSW Health's *Service Framework: to improve the health care of people with intellectual disability* (2012) and funding of three new pilot intellectual disability health teams.

NSWCID's decision to instigate the National Roundtable on Quality and Safeguarding followed the success of the National Roundtable on the Mental Health of People with Intellectual Disability that we led in 2013 with support from the then Department of Health and Ageing.

NSWCID's advocacy on national issues links in with our collaboration with our colleagues from around the country in Inclusion Australia.

At present, the availability of advocacy around Australia is poorly distributed geographically and nowhere adequate to meet the need for it. There are particular concerns about advocacy's future by those of us funded by the NSW Government since it has contracted to hand over its whole disability budget to the Commonwealth.

The NDIS Quality and Safeguarding Framework should include a plan to ensure an adequate supply of advocacy around Australia. This should include specific systemic advocacy for people with intellectual disability.

See our blog on why people with intellectual disability need their own systemic advocacy bodies at:

nswcid.blogspot.com.au/2015/02/people-with-intellectual-disability.html

Block funding of advocacy is essential because:

- Individual and systemic advocacy will continue to have just as much of a role with people with disability who are not NDIS participants as with those who are participants.

- The need for advocacy often arises in unforseen and urgent circumstances, for example trouble with the police or a grievance with a support provider.

- Advocacy is often vital to speaking out on behalf of people with intellectual disability who are at risk but have very limited ability to see that risk.
- Systemic advocacy around Australia will be very important to ensuring action by States and Territories on the National Disability Strategy.

It is inappropriate for advocacy to be funded by only one level of Government, as would flow from the NSW Government's current intention to hand over all advocacy funding to the Commonwealth. Advocacy needs diverse sources of funding to avoid the danger that, over time, the one funder skews the focus of advocacy towards the priorities of that funder.

Key Points

Individual and systemic advocacy are essential parts of a quality and safeguarding framework.

The final framework should include a plan to ensure an adequate supply of advocacy around Australia.

NDIA Provider registration

People must watch out for some support providers.
They will say everything and anything to get your business.

Support providers should at least be required to comply with an NDIS code of conduct and additional conditions that vary with the circumstances. The code of conduct should include mandatory reporting of workers who may not be safe to work with people with disability.

NSWCID agrees with the principle that safeguards should be proportionate to risk. However, risk does not only relate to the kind of support a provider offers. Equally important is the vulnerability of the service users related to factors such as cognitive impairment and communication skills. The extent of registration requirements should not be determined by the nature of the service alone.

We are sceptical about the effectiveness of reviewing service quality on the basis of reviewing providers' policies and procedures. (McEwen and others 2014) Policies and procedures are important. However, our experience is that they are often overly complex and prescriptive rather than providing a framework for good judgements by staff. Also, our impression is that policies and procedures are often prepared to meet auditing requirements in a way that is detached from the on the ground needs of service users.

Providers should generally have to undertake independent quality evaluation with central emphasis on:
- in-depth interviews with individuals and their families and other natural supports
- interviews with client committees
- interviews with and observation of support workers to gauge how they are responding to the needs and choices of people with disability including through evidence based practices such as person centred active support
- observation of practice leadership within the provider.

Key indicators of a quality service should include:

- the degree to which provider practices are shaped by service users and, where appropriate, their families, for example by:
  - consultation about provider practices
  - service users having a role in staff training
  - user committees with independent support
  - service users feeling empowered to provide negative as well as positive feedback in relation to their support
- the degree to which Indigenous people and those from culturally and linguistically diverse backgrounds see the support provider as aware of and responding to their particular needs
- the degree to which the provider successfully supports people to achieve outcomes based on their goals and aspirations
- the degree to which individuals have choice and control in relation to how supports are delivered to them, for example a choice in which staff provide support to them. (This last point was emphasised by participants in the focus group of people with intellectual disability at the NSWCID Roundtable.)

Quality evaluation reports should be made public so as to assist people with disability to choose providers.

The NDIA should administer the quality evaluation system.

It may be appropriate to exempt from independent quality evaluations providers of support with low risks to service users.

We would also welcome the development of a voluntary quality assurance system that would complement what is covered in mandatory quality evaluation.

People with intellectual disability get put in a box.
Support staff need training on how to support people.

Key Points

Registration requirements should be related to risk but risk is related to vulnerability of service users not just service type.

Providers should generally be required to undergo independent quality evaluation based on the experiences and outcomes of users and observation of service practices.

Systems for handling complaints

Providers should be obliged to have accessible internal complaints systems. However, an external and independent complaints body is also vital so as to provide a reasonable level of accountability for vulnerable and commonly disempowered clients of services.

A balance needs to be struck in relation to the desirability of a person with disability having a one stop independent complaints shop and the importance of mainstream complaints agencies being accessible to people with disability. At the minimum, the independent disability complaints body should be able to provide warm referrals to other complaints bodies and have a systemic role in promoting and monitoring their disability accessibility.

The independent body should be able to deal with complaints in relation to the NDIA as well as support providers since the one complaint may often raise issues about the actions of both the NDIA and the support provider. Also, NDIA staff undertake some roles very similar to support providers, in particular planners and local area coordinators.

There should be a statutory prohibition against reprisals against complainants including whistleblower protection provisions.

"Complaints body" is too narrow a label for the kind of independent rights protection body that is needed. A high proportion of people with disability, in particular intellectual disability, tend to lack awareness of their rights, what are rights infringements, and what steps they can take to pursue their rights. Due to their dependence on providers, they also tend to be scared to complain. Similar observations can be made about many family members who have over decades been made to feel grateful for and dependent on whatever services they have been able to find.

The independent body therefore needs to have at least a 50% focus on proactive rights/quality protection through:

- monitoring of providers
- individual and systemic reviews
- own motion inquiry powers
- systemic reviews
- researching and promoting good practice

See for example the powers of the NSW Disability Commissioner in the Community Services (Complaints, Review and Monitoring Act 1993 NSW sections 11, 13, 14A)

We support the other proposed functions of the complaints body spelled-out under Option 3 in the proposed framework.

In its complaints and other roles, the independent body's central focus should be on:

- quality of outcomes for people with disability, and
- active respect for their rights,

rather than the policies and procedures of providers.

It should have a problem solving approach whilst also conducting rigorous investigations where appropriate.

The independent body needs to have its independence assured by its head having statutory security of tenure, annual reports to parliament and having complete control over its staff and budget.

A community visitor scheme is a very valuable monitor, builder of natural safeguards and link to the independent body. Visitors need statutory powers to enter service premises unannounced and inspect records. See for example Community Services (Complaints, Appeals and Monitoring Act) 1993 NSW Part 2.

Visitors should either be directly attached to the proposed independent body or a similar state body such as a public advocate.

In NSW, community visitors receive modest remuneration. We understand that this is not so in other states. In view of the heavy responsibilities of the role, visitors should be reasonably remunerated.

Key Points

While providers should have accessible complaints mechanisms, an independent complaints body is also essential.

However, in view of the many reasons why people with intellectual disability do not make complaints, the independent body needs to focus at least 50% of its role on proactive monitoring, reviews and inquiries. There should be a community visitor scheme linked to the independent body.

The independent body should be focused on the NDIA as well as providers and should have a role in linking people to and up skilling mainstream complaints bodies.

The central focus of these structures should be on quality of outcomes for people with disability and active respect for their rights rather than on the policies and procedures of providers.

Ensuring staff are safe to work with participants

Questions

- Who should make the decision about whether employees are safe to work with people with disability?
- How much information about a person's history is required to ensure they are safe to work with people with disability?
- Of the options described above, which option, or combination of options, do you prefer?

Providers of support should have the primary responsibility for selection and monitoring of staff.

People with disability, particularly people with intellectual disability, are very vulnerable to neglect, abuse and exploitation. This ranges from the neglect inherent in a lack of meaningful activities through low-level, cumulative harassment and intimidation through to high level sexual and physical abuse. There is a range of evidence that people with intellectual disability suffer high levels of neglect, abuse and exploitation including in the often closed environments of support provision.

There do need to be external controls on who should be allowed to work in disability support.

There should be mandatory reporting of allegations and reasonable suspicion of serious abuse and neglect in support providers, including unexplained serious injury to a person with disability. Also, the proposed independent quality assurance system should specifically focus on whether support providers are taking action to minimise and appropriately respond to abuse, neglect and exploitation.

Improved data on the incidence of abuse and neglect should be gathered through mandatory reporting.

Employers should be required to obtain referee and police checks for all staff who will have client contact. However, these are minimal safeguards in view of the vulnerability of people with intellectual disability and the various reasons why mistreatment of people with intellectual disability seldom lead to criminal convictions.

We support a requirement for working with vulnerable people clearances at least in relation to staff who have client contact. Decisions should be based on a wide range of information similar to the current South Australian System. The available information should include a centralised database of findings of misconduct against individual disability workers.

Information should be drawn from other countries in relation to migrant workers.

An appropriate test for providing clearances may be whether a person "may pose a risk" or an "unacceptable risk" to clients of providers. A "beyond reasonable doubt" or even "balance of probabilities" test would be too lenient.

Whatever the test for clearances, employers should retain responsibility for satisfying themselves that a prospective employee is appropriate for a particular job. To assist with this, employers should check whether a prospective employee has any adverse finding on the proposed centralised data base. The employer could then consult the previous employer who notified the finding. The NSW Ombudsman could provide further detail about this approach which applies to employment in children's services in NSW.

Preferably, one scheme should cover people who wish to work in disability support, children services or aged care.

The scheme should be statute based with a right of independent review by an appropriate tribunal.

The Fair Work Act should be amended to make it clear that an employer is obliged to terminate the employment of a person who does not have a working with vulnerable people clearance.

Key Points

There should be mandatory reporting of allegations and reasonable suspicion of serious abuse and neglect in support providers.

Staff should need vulnerable people clearances based on a wide range of information similar to the current South Australian System. The available information should include a centralised database of findings of misconduct against individual disability workers. Prospective employers should be able to contact previous employers via this database.

Safeguards for participants who manage their own plans

> **Questions**
>
> - Should people who manage their own plans be able to choose unregistered providers of supports on an 'at your own risk' basis (Option 1) or does the NDIS have a duty of care to ensure that all providers are safe and competent?
> - What kind of assistance would be most valuable for people wanting to manage their own supports?

As the proposed framework says, there are a number of options for who manages a participant's plan:
1. The participant
2. A plan nominee (eg a parent of a person with intellectual disability)
3. A registered plan manager
4. The NDIA.

1-3 are collectively called self-management in the framework. They are all extensions of the degree of choice and control that the participant has over their supports and therefore strongly consistent with the purpose of the NDIS. The Productivity Commission also recognised the beneficial impacts of self-management on the service system, anticipating that it would reduce the demand for formal service and cost less than other alternatives.

Rees (2013) asked people who were self-managing their packages what type of assistance they believed would be valuable for other people who were thinking about self-management. Responses included:

- Support for proactive thinking about what a good life might look like including assistance to develop a vision and strengthen informal support.
- The opportunity to connect with others who are self-managing.
- Having clear information about what self-management entails including from personal, financial and administrative perspectives.

In England, Scotland and Sweden, a range of strategies is in place to support people to self-manage and minimise risks of abuse and exploitation (Goodwin 2014). These include

- Direct payment support services which provide a range of services to assist and safeguard employment of support workers, assist with financial responsibilities, train self-managers and other matters.
- Information resources for self-managers and encouragement for them and their support staff to participate in training.
- Development of supported decision making skills.
- In Scotland, it is an offence for a person barred under the Protection of Vulnerable Groups (Scotland) Act 2007 to work for a self-managing person.

The NDIS should provide a range of assistance and incentives for self management:

1. **Use individual planning processes to facilitate a thorough exploration of risk enablement and safeguards.** Every planning process with the NDIA and with providers should include a discussion of what might go wrong and strategies to safeguard the individual. This should include considering risks of employing unsuitable staff. The planning process should not be rushed. Participants and families should be given flexibility and time to think up safeguards that suit their situations.

2. **Provide skilled assistance with the implementation of the plan and support**. When a participant chooses to self manage their plan, funding should be provided to purchase skilled support to implement their plan.

3. **Encourage the development of registered plan manager organisations** that share the management of support with the participant or their plan nominee. To date, this option is poorly understood and hardly used by NDIS participants. However, it is consistent with approaches available in Britain and Sweden and with shared management systems that have been available through State and Territory disability service systems for many years. Under these systems, a service is the fund holder and employer of staff, and responsibilities for aspects of support management are delegated to people with disability and families in accordance with their abilities and wishes.

4. **Provide clear information to assist people to use self-managed options**. The NDIA should develop resources that encourage and support people to use self-management. These resources could be on line and should be backed up by a telephone advice line.

5. **Facilitate the development of user-led organisations that supports people to self-manage.** Glasby and Duffy (2007) reported that where direct payments have been taken up enthusiastically, a key factor has been a user-led centre for independent living to provide advice and peer support for people who are interested in self management. Disability Support Organisations (DSOs) have the potential to take on this role. DSOs being based in particular communities give them particular advantages in supporting self-management by people who have multiple disadvantages

As time goes on, many family members may seek to become a participant's nominee with a view to managing the NDIS plan or engaging a registered plan manager to do so. NSWCID would generally welcome this.

However, for a family member to become a plan nominee, they need to comply with requirements in the NDIS legislation. These requirements need to be followed very carefully by the NDIA. We are concerned that the NDIA might too readily accept the suitability of an uninformed or overprotective family member to be nominee.

We are cautious about requiring self managing participants to only use NDIS registered providers even with relaxed registration requirements. The emphasis should more be on equipping and supporting self-managing participants to make informed planning decisions, including in relation to risk management.

Many self managing participants are likely to choose to use registered providers partly because of the safeguards inherent in registration. However, for a wide range of good reasons, other participants may choose to use unregistered providers.

There should be a capacity for disability workers to be excluded from working for self managing participants on the basis of things like relevant criminal records and histories of mistreatment of vulnerable people.

Other structures in the framework proposal would also provide some safeguarding of self-management including complaints and monitoring systems and regulation of restrictive practices.

Finally, there is a safeguard in the NDIA's power to refuse a person's wish to self manage if there would be an unreasonable risk to the participant.

Key Points

The NDIS should provide a range of encouragements and supports for self management including developing people's skills in risk enablement, information packages for participants, skilled assistance with implementation of a plan and fostering development of registered plan managers and user-led organisations that assist people to self manage.

The nominee regime in the NDIS legislation should be applied rigorously to confirm proposed nominees have the required attributes.

Self managers should not be confined to using registered providers of support but unsafe workers should be excluded from working for a self manager.

Reducing and eliminating restrictive practices

Authorisation

> **Questions**
>
> - Who should decide when restrictive practices can be used?
> - What processes or systems might be needed to ensure decisions to use restrictive practices in a behaviour support plan are right for the person concerned?
> - Are there safeguards that we should consider that have not been proposed in these options?
> - For providers, what kinds of support are you receiving now from state and territory departments that you think would be helpful if it was available under the NDIS?

Existing authorisation and monitoring regimes for restrictive practices have been established in a context of often poorly funded and lowly skilled disability support. The NDIS should mean that these assumptions no longer apply so that restrictive practices will much less often be perceived as needed.

However, this evolution requires considerable development of the disability workforce both in quantity and quality (and ensuring that NDIS funding packages are adequate to pay for expertise in behaviour support).

One key need is a strong workforce of behaviour support practitioners. The NDIS should establish clear criteria for what professional qualifications and competencies are required to be a behaviour support practitioner and a workforce development plan to ensure that there is an adequate supply of practitioners. One of the required competencies should be in person centred active support.

The list of dot points under the heading *Our aim* in the proposed framework is a good starting point for the necessary requirements of quality and safeguarding in relation to restrictive practices.

However, the following additional points should be added:
- A restrictive practice should not be permissible in the absence of person centred active support and a comprehensive positive behaviour support plan.
- A behaviour support plan should always be informed by:
    - A review of the reasons for and function of the behaviour and
    - A medical review by a doctor skilled in working with people with intellectual disability – is there is any physical or mental health contributor to the behaviour?

- Any prescription of psychotropic medication should be made by a doctor with specific competencies in the mental health of people with intellectual disability and as part of a collaborative decision-making approach with a behaviour support practitioner
- Where a person has complex challenging behaviour, multidisciplinary collaboration will often be vital including for example a speech pathologist, an occupational therapist and a psychiatrist. (NSWCID 2013)
- Any behaviour support plan including a restrictive practice should include a process for reducing and eliminating the use of the practice.
- Input of families and other advocates are important to development of behaviour support plans. However, it also needs to be taken into account that many families are not well informed or empowered in relation to behaviour support issues.

In principle, it is highly inappropriate for decisions about restrictive practices to be made by staff of a support provider, including if they have had the input of an independent professional chosen by the provider. There is a conflict of interest here. The only argument we can see against authorisation being required from an independent body or guardian is the extremely large number of people currently subject to restrictive practices in Australia.

In NSW, the combination of government policy and a role developed by the guardianship system means that physical and mechanical restraint and seclusion should only occur with the consent of a guardian specifically appointed for this purpose. The consent of the Tribunal is also specifically required for libido reducing dedications. The caseload is easily manageable.

However, the NSW system does not require consent of a guardian for chemical restraint which comprises the overwhelming majority of restrictive practices in Australia. Chemical restraint is the predominant reported restrictive practice in Victoria. 95% of those restricted are receiving chemical restraint. (Office of the Senior Practitioner 2011)

In NSW, whether psychotropic medication is characterised as being for chemical restraint or treatment of a mental disorder (itself not a clear distinction), consent is required from a "person responsible". This is usually a closely involved family member unless a guardian has been appointed for medical consent purposes. The rigour of these consents as a safeguard varies greatly with how informed and confident family members are in dealing with these decisions.

In principle, our view is that restrictive practices should only occur with authorisation from either an independent official such as a senior practitioner or consent of a guardian appointed for this purpose. However, we do recognise the challenge of the numbers involved here and are concerned that a requirement for such approvals would create a workload that could not be met with any sort of quality in decision-making.

If there are to be some situations where people within service providers are authorised to approve restrictive practices, there are at least need to be very rigourous independent processes for deciding whether a person has the high levels of competencies in positive behaviour support to be so authorised.

An alternative approach would be to broaden the approval process to a panel which also includes an independent duly qualified professional and an independent advocate experienced in behaviour support.

In any case, there should be safeguards including a capacity for independent review and overturning of authorisations of restrictive practices and/or a backstop that, if a guardian has been appointed with a relevant decision-making function, then that guardian's consent is also required for the use of the restrictive practice.

At present, at least in NSW, the quality of behaviour support around the state is highly dependent on a range of structures, multidisciplinary skills and expertise within ADHC, the State government disability services agency. Also, ADHC has funded two chairs at UNSW that are playing extremely valuable roles in enhancing behaviour support and the related issue of intellectual disability mental health. With the NSW government being committed to cease being a disability service provider, the NDIS needs to ensure that there is very robust similar system created outside the state government structures. We see maintenance of the UNSW chairs as a vital part of this.

Monitoring and reporting

Questions

- Would you support mandatory reporting on the use of restrictive practices? Why/Why not?
- If you support mandatory reporting on the use of restrictive practices, what level of reporting do you believe should occur?

We support establishment of a system for mandatory reporting of restrictive practices based on the Restrictive Interventions Data System in Victoria. This system would need to be supported by a Senior Practitioner or equivalent with a skilled team of professionals who can collate and analyse the data and carry out audits and reviews of concerning trends in relation to particular providers or particular individuals.

This system should extend to a capacity to require independent approval of restrictive practices for some individuals either by the Senior Practitioner or via a guardianship application.

The Senior Practitioner should also have a well resourced power to conduct random audits and then work with providers to enhance their positive behaviour support and decisions in relation to restrictive practices.

Part of the role of a community visitor scheme should also be to identify situations where restrictive practices are being used inappropriately or without authorisation and to report this to the Senior Practitioner.

Other key issues

What about other restrictive practices?

The National Framework on restrictive practices and the Proposed Quality and Safeguarding Framework focus predominantly on restraint (physical, mechanical or chemical) and seclusion. There is a range of other restrictive practices used to address challenging behaviour including:

- confining a person to their home, in some cases by having the doors locked whenever the person is at home
- restricted access to spaces within the person's home or to items belonging to the household or the person
- monitoring devices.

Confining a person to their home without legal authority via guardianship or other specific legislation may amount to false imprisonment. Restricting a person's access to their own chattels may be unlawful as "detinue".

Further consideration is needed of which restrictive practices are covered in an NDIS regime and how, and issues of interplay with existing State/Territory legislation such as the Disability Act Vic Part 8.

The distinction between chemical restraint and mental health treatment

There is not a clear distinction between 'chemical restraint' and use of psychotropic medication to address a mental disorder (NSWCID 2013):

- Mental disorders are very hard to diagnose in a person with intellectual disability and limited verbal communication.
- There are very limited skills in intellectual disability mental health in GPs and psychiatrists.
- The distinction can be in the eye of the beholder. What one doctor may call chemical restraint, another may call treatment for anxiety.
- Because the distinction is unclear, it is open to abuse.
- There can be pressure on doctors to specify a mental disorder diagnosis so that medication is available under the PBS.

Therefore, the quality and safeguards framework should include a focus on all prescription of psychotropic medication to people with intellectual disability rather than just on what a doctor characterises as chemical restraint. This should include a focus on:

- Doctor skills
- Cross disciplinary collaboration between behaviour practitioners, doctors and other relevant professionals.
- The general need for a positive behaviour program whenever psychotropic medication is used, not just when it is characterised as chemical restraint.

The role of the Senior Practitioner or equivalent should include proactive systemic action to improve decision-making by doctors in relation to psychotropic medications for people with disability and the capacity to seek appointment of a guardian for medical decisions where appropriate.

Apprehended violence orders against people with disability
In NSW, it has become quite common for a supported accommodation worker who has been assaulted by a person with intellectual disability to call the police who then take out an AVO against the person. This is problematic since the root cause of the problem may well be inadequate general disability support and inadequate behaviour support. Also, the person may well not understand the AVO process or the implications of the order. Challenging behaviour becomes criminalised.

This situation needs to be addressed in quality and safeguarding including by compulsory reporting of AVOs to the NDIS Senior Practitioner or equivalent.

Key Points

Workforce skills - The NDIA needs to develop a strong workforce of behaviour support practitioners who meet rigorous criteria for professional qualifications and competencies.

The NDIA needs to maintain the structures or at least roles of State/Territory regimes that underpin quality behaviour support.

Authorisation - Restrictive practices should only be allowable in the context of high quality behaviour assessment and support.

Any prescription of psychotropic medication to a person with intellectual disability should be made by a doctor with established competencies in intellectual disability mental health.

Restrictive practices should only be permissible with the authorisation of an independent official such as a senior practitioner or a guardian who has been appointed for that purpose.

If there are to be any situations where providers have the power to authorise restrictive practices, there need to rigorous safeguards in relation to the skills of the authoriser, independent monitoring and/or involvement in decisions, and review rights.

Monitoring and reporting - There should be mandatory reporting of restrictive practices similarly to the Restrictive Interventions Data System in Victoria. A senior practitioner should monitor the data and conduct reviews and spot audits aimed at enhancement of providers' behaviour support and intervening where restrictive practices are being used inappropriately.

Which restrictive practices? - The proposed framework is focused predominantly on restraint and seclusion. There are other restrictive practices such as monitoring devices, confining a person to their residence and apprehended violence orders. Further consideration is needed of which practices are covered by the NDIS framework and how.

Chemical restraint versus mental health treatment - This is not a clear distinction. The framework needs to include a focus on improving doctor skills in intellectual disability mental health and collaboration between doctors and behaviour support practitioners.

Oversight of the NDIS and the National Disability Strategy (NDS)

> **Questions**
> - Should there be an independent oversight body for the NDIS?
> - What functions and powers should an oversight body have?

How do we make the NDIS accountable?

The NDIS is a massive social and economic reform. With good reason, it is being rolled out quickly across Australia. The complex and competing pressures on Governments, the NDIA board and management and support providers through this period of change cannot be underestimated.

An independent oversight body is needed to safeguard this process and to deal with issues such as complaints and restrictive practices.

The NDIS should have an independent oversight body bringing together roles spelled-out in this position relating to:

- complaints, monitoring and review, and identifying systemic problems including market failures
- community visitors
- monitoring of a mandatory quality evaluations scheme and fostering of a voluntary quality assurance scheme
- mandatory reporting of serious incidents
- decisions in relation to clearances or appropriateness of staff to work with people with disability
- restrictive practices – authorisation, monitoring and enhancement of practices of support providers and doctors

The body should also have a broad oversight role in relation to implementation of the National Disability Strategy (NDS) by governments around Australia. Despite all current efforts by Governments, there is a clear danger that Commonwealth/State divisions of responsibilities and fluctuating political agendas will undermines action on the NDS causing detriment to people with disability and undue pressure on the budget of the NDIS.

People with disability and all governments would benefit from having an independent, apolitical body promoting action on the NDS by

- Research and best practice development
- Monitoring action on the NDS across Australia
- Promoting enhanced action

The oversight body should be called the Disability Commission and be a stand alone body rather than attached to an existing organisation. This is essential to ensuring that the body develops a culture and practices that are person focused and properly take account of the vulnerability of people with disability and the numerous reasons why people with disability and their families may not make or pursue complaints.

Existing bodies such as the Commonwealth Ombudsman and the ACCC have very important roles in relation to complaints about government and commercial entities. However, a very different approach is needed by people with disability.

The Community Services Division of the NSW Ombudsman does have many of the roles we are suggesting for a Disability Commission. The culture and practices of these roles are safeguarded to some degree by having a separate Division and by the legislative structure for the Division. However, crucially, the Community Services Division operated as a stand alone Community Services Commission for the first years of its life. The Commission was able to establish its own culture and practices focused on the vulnerability, human rights and needs of children, young people and people with disability.

The Disability Commission should have a branch in each state and territory and have a mandate for close consultation with people with disability, advocacy and representative bodies, and providers of support. The body should tap into the expertise of people with disability and their families and advocates, for example in staff training and complaints training for other organisations.

The Disability Commissioner should have similar statutory powers to the Commonwealth and NSW Ombudsmen, have security of tenure for a five-year term and make annual and special reports to Parliament. The Commissioner needs to have a strong background in the protection of the rights of people with disability and established values in line with the objectives and principles in the NDIS Act.

Key Points

There should be an independent Disability Commission oversighting the NDIS and the National Disability Strategy.

The Commission's roles should include those in this Position relating to complaints, monitoring and review, mandatory reporting of serious incidents, working with vulnerable people clearances and restrictive practices.

It is essential that the Disability Commission is a stand alone body so that it can create a culture and practices that are fit for purpose.

Implications of national framework for existing State/Territory rights protection bodies

Careful consideration is needed of what happens to State/Territory safeguards with the implementation of the NDIS. For example, in Victoria, the Public Advocate has a much broader role than the Public Guardian in NSW, including individual advocacy. These local bodies have stood the test of time and should be maintained in a robust form.

In NSW, the Ombudsman has a separate division focused on community and disability services with a wide range of roles many of which might be taken over by a national oversight body but others may not. For example, the NSW Ombudsman has a role of reviewing deaths in supported accommodation which has been invaluable to highlight systemic problems in both disability and health services. It is vital that this role be maintained either as a national role or in the NSW Ombudsman.

Key Points

Care is needed that valuable roles played by State/Territory rights protection bodies are not lost with the implementation of the NDIS, for example the role of the NSW Ombudsman in reviewing deaths in supported accommodation.

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APPENDIX
Participants - National Roundtable on Quality and Safeguarding and People with Intellectual Disability, March 2015

People with intellectual disability

Dianna Khoury
Genny Haines
Tracey Sammutt
Philip Venn
Mark Rothery
Carmello Raspanti

Intellectual disability peaks

NSW CID	Michael Sullivan	Chairperson
	Maria Circuitt	Past chairperson
	Aine Healy	ED Advocacy
	Jim Simpson	Senior Advocate
Inclusion Aust & VALID	Kevin Stone	President
SACID	Richard Bruggemann	Board member
Parent to Parent Qld	Jodi Wolthers	General Manager
Down Syndrome Aust	Ruth Webber	CEO

Cross Disability Alliance

PWDA	Jess Cadwallader	Advocacy Project Manager
NEDA	Brian Cooper	Project Officer
FPDN	June Riemer	Deputy CEO
WWDA	Iva Strnadová	Board member

Other disability community groups

ID Rights Service	Janene Cootes	EO
ASID	Angus Buchanan	President
Disability Network Forum	Carolyn Hodge	Senior Policy Officer, NCOSS
NDS	Gordon Duff	General Manager, Policy and Research

Government

NDIA Board	Bruce Bonyhady	Chair
NDIA IAG	Sylvana Mahmic	Member
NDIA	Lisa-Jane Moody	Director, Quality, Sfgds & Provider Registrn
DSS	Bryan Palmer	Group Manager, NDIS Group
	Bruce Smith	Branch Manager NDIS Group
	Annette Gath	Director, Quality and Safeguards Team
FACS NSW	Annemarie Dwyer	Exec Director, Individualised Options

Rights protection agencies

Ombudsman NSW	Steve Kinmond	Dep Ombudsman & Dis Services Com.
	Kathryn McKenzie	Director, Disability
	Lyn Porter	Community Visitor
Disability Services Commission Vic	Miranda Bruyniks	Deputy Commissioner
	Tamara Reinisch	Chief Adviser
OPA Vic	Colleen Pearce	Public Advocate
Public Advocate Qld	Jodie Cook	Public Advocate
Senior Practitioner Vic	Frank Lambrick	Senior Practitioner
Ombudsman Cth	George Masri	Senior Assistant Ombudsman

Other

UNSW	Leanne Dowse	Chair in ID & Behaviour Support
Southern Cross Uni	Sally Robinson	Research Fellow
UQ	Karen Nankervis	Centre of Excellence Behaviour Spt
Consultant	Belinda Epstein-Frisch	